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# Surviving the Rollercoaster: The Joys & Sorrows of Families of Children with Disabilities

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# Purposes of the Day

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- Concept of “Chronic Sorrow”
- Processes families use to manage their sorrow
- Ways you can provide support
- Ways you can prepare yourself

# Personal Reflection

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Imagine that you had a baby yesterday and that you have just been told that the child has a condition which means she will not grow and develop like other children and will always require care and support from others.

- How do you think you would respond?
- What sorts of processes do you think you may go through?

# Holland or Beirut?

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Many families find themselves to be more cohesive, stronger, and with a newfound sense of purpose in their lives.



Others continue to hurt profoundly.

# “Chronic Sorrow”

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*Prolonged Grief* is a long-term reaction to a single loss.

*Chronic Sorrow* is a reaction to multiple losses over time.

- A perception of sadness or sorrow over time in a situation with no predictable end;
- Sadness or sorrow that is cyclic or recurrent;
- Sadness or sorrow that is triggered internally or externally and brings to mind a person’s losses, disappointments or fears;
- Sadness or sorrow that is progressive and can intensify
- Continues as long as the disparity created by the loss remains

# Overview of the Chronic Sorrow Model

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## Basic Model:

- Antecedents – Cause
- Trigger events
- Internal & External Management Methods

# Antecedents

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- Involvement in an experience of significant loss
  - Loss may be ongoing with no predictable end – “living loss”
  - May be a single loss
  - Includes both actual and symbolic losses
- Gap between the actual reality and idealized
  - Experience the loss in “bits & pieces”

## Trigger Events (“Milestones”)

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- Circumstances, situations, and conditions that bring the negative disparity resulting from the loss experience clearly into focus or that exacerbate the experience of disparity.
  - Differ from accepted norms – social, developmental, or personal
- In bereavement situations, the disparity is created not by the presence of the individual, but their absence.

# Stressors Experienced by Families of CWD

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- Changes in family functions: role changes, finances, marital satisfaction. Both the individual and family identity has to be redeveloped or transformed.
- Interactions with professionals
- Severity of the disability (i.e. Children who are unable to effectively communicate their needs, are incontinent, or who have sleep problems, dependent for basic needs beyond “traditional” timelines.)
- Pressure to make life or death decisions often with limited or confusing information

# Relieving Stress

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- What are things that you do to relieve stress?
- How might families of children with disabilities find the time to do these things?
- What if they don't?

# Cognitive Coping Theory

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- Ways in which individual family members may change their subjective perceptions of stressful situations.
- Three dimensions of cognitive adaptation
  - Causal Attributions
  - Mastery
  - Enhancing Self-Esteem

# Causal Attributions

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The search for the cause of an experience in order to establish or reestablish a sense of control and/or a sense of the orderliness and predictability of the environment.

- The search for “meaning” or purpose
- Appear to “shopping” for a diagnosis – especially if the child has a global diagnosis like a “learning disability” or “Cerebral Palsy”
- Can be positive or negative
- Even “self-blame” can be associated with positive adjustment because it helps establish control of the situation in the future.

# Mastery

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Involves gaining a feeling of control over the threatening event so as to manage it or keep it from occurring again.

- Internal Control:
  - Information control
  - Behavior control
- What may be some ways that you can contribute to parents achieving “mastery”?

# Enhancing Self-Esteem

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Achieved through selectively attending to the positive aspects or benefits of a situation, and/or comparing oneself positively to others.

- Establishing “cognitive” or “retrospective” control of a situation
- Family focuses on the benefits of a situation – finds a “silver lining”
- Comparing oneself favorably to others

# Implications for Family-Professional Relationships

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- Some animosity between parents and professionals they work with is unavoidable
- Interactions may be stressful because of biases held by the professional, the family, or both
  - The family is, in part, the “cause” of the child’s problem
  - The child is of no worth to the family
  - The family is responsible for everything that happens to the child

# Implications for Family-Professional Relationships (cont.)

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- Professionals who understand the function & value of these coping strategies may not only be able to help families enhance their use, but may gain insight into the family's behavior that may enhance professional's ability to respect and collaborate with the family
  - *Causal Attributes* - don't immediately infer the family is unable to accept the child's disability
  - *Mastery* – If there isn't a sense that interventions or actions by the family or professionals will be useful, the family may not participate
  - *Enhancing Self-Esteem* - Help families identify the positive aspects of having a child with a disability. The catch...YOU have to believe what you're telling them.

# Braving the Rollercoaster: The Joy-Sorrow Concept

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Families experience periods of great joy and satisfaction with their children in between the bouts with sorrow – otherwise the grief would become debilitating.

- A mother says that when she is alone with her son, she feels she is “in the presence of angels”. (Scornaienchi, 2003)
- Parents are lifted up by their children’s positive attitude, their courage and resilience. (Kearney & Griffin, 2001)

# How can you support families?

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- Help them prepare for or work through unexpected recurrences of grief
  - Help them identify what triggers might occur
  - Be mindful when giving diagnoses – good news **and** bad
  - Be honest with them about what they can expect without being overly dramatic
  - Be hopeful
  - Be encouraging
  - Share success stories you've heard
  - Listen to their stories – they need to tell them
  - Talk about things that other children in the family are doing (ask questions)
  - Introduce them to other families, then RE-introduce them
  - Empower them
  - Allow them to grieve

## How can you support families? (cont.)

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- Recognize that what may appear to be a lack of interest may, indeed, be a lack of time and/or energy
  - *Where are the parents? By Sue Stuyvesant*
  - Be responsive to the needs and interests of individual families
  - Identify ways to help relieve some of the pressures within time-stressed families so as to free time for participation in group activities
  - Identify means of participation that are meaningful to the family not time and energy intensive

## How can you support families? (cont.)

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- Remember, the parents know their child best
  - You may be well trained, but they live with the child!
  - Encourage both parents to be flexible and assume key roles – avoid gender specific duties
  - Ask families what their children can do under different circumstances
  - Don't base a child's abilities on their diagnosis alone

## How can you support families? (cont.)

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- Assist families in obtaining adequate information
  - Help them locate information resources
  - Don't sugar coat or leave things out because you think it will be "misused"
  - Help eliminate communication barriers
- Appreciate families' successes without sanctifying them
  - We often imply that parents of CWD are "superhuman"
  - Coping skills that families employ are available to most families and similar to those used to parent any other child.

# Don't forget the siblings!

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Siblings share both the real & symbolic losses right along with their parents, but their attitudes, feelings, and concerns are also shaped by their unique relationships & roles within the family.

- Feelings that they are ignored, displaced or forgotten – this may cause them to act out
- Parents may rely heavily on the “well” child for validation and reassurance – but may also present triggers

## Don't forget the siblings! (cont.)

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- Invite and value siblings' perspectives and input
- Serve as a safe haven or find someone who can
- Reassure them that their negative feelings are okay
- Help parents recognize the individual strengths of their children
- Encourage individual time

# How can you prepare yourself?

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- Just knowing the terminology (i.e. “chronic sorrow”, “compassion fatigue”)
- Develop a partnership with the family
- Know the resources available and be able to share them – and respect the families choice whether or not to access them
- Focus on family strengths
- Share the family’s joys and sorrows
- Develop a support system of your own of some kind
- Develop personal rituals and keep to them

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Thank you!!!!

